Personal Barriers to Seeking Diabetes Self-Management Education in Pitt County, North Carolina

An Internship Report

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By

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Introduction

This report summarizes the results of an internship undertaken to meet the requirements of the MA degree program in Anthropology during the summer of 2013 with the Diabetes Self-Management Education (DSME) program at the Pitt County Health Department in Greenville, North Carolina. I endeavored to accomplish four main objectives during the internship. (1) to learn how public health initiatives help people manage diabetes through self-care, educational interventions and support services; 2) to gain a better understanding of health disparities management within a public health setting; 3) to explore the roles that anthropologists can fulfill in a public health setting; and 4) to utilize anthropological research skills in qualitative data collection and analysis to assist the DSME program with its program goals. Conversely, the DSME program directors were interested in having an intern assist them with gathering data on the reasons why patients referred to the program often did not follow through with the referral, and what potential barriers to participation might exist

Prior to the start of my internship, myself, my academic advisor, and the DSME directors, devised a contract which outlined the following duties that I would compete: 1) to attend the health department orientation; 2) to familiarize myself with literature about the DSME program, diabetes, the standards for diabetes education and self-management, and other appropriate resources; 3) to attend and observe the educational classes, patient counseling sessions and support group session; 4) to familiarize myself with the database management system; 5) to offer office support in the administration of the program; 6) to independently research the reasons why patients referred to the program often do not enroll and why those who do enroll often do not return for classes; 7) to recruit participants for focus groups; 8) to develop, carry out and analyze focus group data on the factors related to non-participation; 9) to develop new methods for

publicizing the program and help with developing promotional materials; 10) to prepare reports and recommendations for the Pitt County Health Department staff from the collected data.

The Internship Setting

The diabetes self-management education program at the Pitt County Health Department is a referral-based program that engages participants in five appointments or classes over the course of one year. It is designed to provide diabetes self-management education in order to help decrease diabetes-related health disparities in Eastern North Carolina. This program is available with a doctor's referral to any person with pre-diabetes, type 1 and type 2 diabetes, or gestational diabetes (Pitt, 2011). The cost of the DSME program is covered for many by Medicaid, as well as some private insurance companies. If neither option applies to the patient, a sliding scale based on household income and number of household members is used to determine the patients' out of pocket cost (Joan Mansfield, personal communication, June 3, 2013). Upon referral, an individual initial in-take appointment is required before patients can attend the two, four-hour group classes. After completing the two classes, a three-month follow up group course is required to assess the level of behavior change related to the patient's diabetes self-management. Also at this point in the program, hemoglobin A1C levels, or the average glucose level in the blood, are tested at the primary care doctor and that information is sent to the DSME program as an additional measure of success in managing their diabetes. The target A1C level is <7%. This step officially concludes the patient's time in the DSME program; however, a one-year maintenance appointment is encouraged to determine if the patient is still following the behaviors that they learned while in the program. All appointments and classes are held at the health department, and are offered every month. A support group is held the second Wednesday of the month from 10 to 11:30 a.m. at the health department. Topics covered in the support group

vary monthly, and include “Virtual Grocery Store Tour and How to Read Labels”, “Dining out with Diabetes”, and “Diabetes: Exploring the Impact on Body, Mind, and Family”. This service is free of charge and open to the public without a physician referral.

Since its start in 2009, the DSME program has received over 224 patient referrals. Of these, 173 are female and 51 are male, and the average age is 52. The youngest person referred is 12 years old, and the oldest is 88 years old. Of the 224 referred patients, 105 are listed as Black/African American, 40 are White/Caucasian, two are Asian/Chinese/Japanese/Korean, and 1 is Hispanic/Chicano/Latino/Mexican with 75 listed as “Do Not Know”, and one listed as “Other”. The majority of people that have been referred have Type 2 diabetes (n=197), nine are Type 1, four have Gestational diabetes and five are listed as Pre-Diabetic. One is listed as “Other”, and eight are listed as “Do Not Know”. The individuals listed as “Do Not Know” are either referrals that have never made an appointment for the initial assessment, or in the case of race and ethnicity, the information has not been entered into Chronicle, their record keeping program. (Joan Mansfield, personal communication, May 29, 2013). To date, 55 individuals have completed the program, and 90 have had at least an initial assessment but have not completed the three-month follow up. Out of these, 70 cases have been closed, leaving 20 that are in the process of going through the program. Seventy-eight people have been referred but have NEVER been seen for the initial assessment (Joan Mansfield, personal communication June 5, 2013).

Programs like the diabetes self-management education at the health department can have a vital role in the overall health of a community. Determining how to attain a higher level of patient participation and retention to these programs could not only assist in maintaining healthier communities by managing diabetes, but could also lead to lower mortality rates

associated with diabetes and comorbidities. The question of participation and retention will be addressed in the following section

Internship Activities and Responsibilities

I completed the internship between May 28, 2013, and August 16, 2013, for a total of 162 hours. I worked under the supervision of Joan Mansfield, the nutrition director, and Robin High, a registered nurse diabetes educator. During my time there, I offered support for the staff by making copies, putting together pamphlets and mailing reminders for the monthly support group. Of the agreed upon duties decided on in the beginning, the only one that I was not involved in was to develop new methods for publicizing the program and help with developing promotional materials. I did touch on this topic during the focus group, and I have included the information in a following section of this report. I also had frequent interactions with individuals in other roles in the health department, including the Special Supplemental Nutrition Program for Women, Infants, & Children (WIC). I began with an orientation that is required of all employees of the health department, and spent time familiarizing myself with the literature on the standards for diabetes self-management education. Throughout the internship process, my supervisor invited me to participate in, and observe all meetings and classes in which she herself was involved. At the health department, I attended one nutrition division meeting and one general department during the internship period. I was also able to attend two meetings of the Pitt Partners for Health, of which the diabetes team, Dr. John Morrow, the health department director, and several other department staff are members.

Within the DSME program, I observed six initial appointments with new referrals, assisted in setting up and attended three of the monthly support groups, and observed and participated in five of the DSME classes. I sat in on two monthly webinars, one with my

supervisor and one with the five-member diabetes education team. I also attended two of the monthly diabetes education team meetings. In addition, I attended a meeting between the DSME program and Health Assist, a community health collaboration that assists uninsured individual with health care services and costs. For the majority of the meetings I only observed, but in several, I was able to take on a participatory role. In each of the two diabetes team meetings, the nutrition division meeting, and the department meeting, I was required to give a report on the progress of the focus group that I would be conducting. After observing several DSME classes, my supervisor asked for a brief report on my observations, particularly how the patients reacted to the classes, and my reflections on how the classes were taught. I prepared a report and sent it to my supervisor to go over during the second team meeting. I also gave a brief presentation of my role and proposed research at one of the Pitt Partners for Health meetings.

During initial appointments with new referrals, I assisted Joan Mansfield in printing pamphlets, making copies of patient prescriptions, and getting drinks or snacks for the patient if needed. For support group sessions, I assisted in choosing the recipe for the food demonstration, setting up the room, including refreshments. I also created a PowerPoint for one of the support group sessions on how to choose healthy foods when dining out. I assisted my supervisor and other diabetes team members in setting up for the DSME classes by preparing lunch plates for each patient, and organizing and setting out course materials and resources. After observing two classes, the diabetes educators asked me to participate, as the class is intended to be hands on and involve the patient in discussion as much as possible. By utilizing participant observation, I was able to gain insight into the process of the DSME program, both from the perspective of the diabetes educators and the patients. In addition to meetings and classes, my supervisor assigned to me several other responsibilities over the course of my time there. One of the main tasks was

to call patients to schedule them for classes and to make reminder calls for class. All information then had to be updated in Chronicle, the patient record database. I also gathered information for and updated a resource list that the diabetes educators can provide to patients with resources such as eye doctors, food banks, and local support groups. This involved checking websites and calling companies, organizations, and doctor's offices to update contact information and.

Literature Review

Diabetes is a chronic disease that is found in many parts of the world, with over 371 million people diagnosed as of 2012 (Abubkari, 2013:617). Type 2 diabetes constitutes 85% to 95% of diabetes cases worldwide (Steinsbekk, 2012:2). Although medication is frequently required to control blood glucose levels, many individuals with type 2 diabetes can actively manage their disease by maintaining a healthy lifestyle. This includes a balanced diet, exercise, using caution with over the counter medications, and being aware of the risk for concomitant diseases such as heart disease, stroke, amputations, and blindness (Vaccaro, et al, 2012:2, CDC, 2012). While a doctor can assist in educating the individual about the behavior changes necessary for disease management, many do not provide the comprehensive education that the patient needs. Diabetes self-management education programs (DSME), such as the one offered by the Pitt County health department, are an alternative to doctors for patient self-management education. The DSME programs utilize group classes and individual counseling for patients with pre-diabetes, type 1, type 2, and gestational diabetes, although the majority of patients have type 2. The DSME curriculum covers such topics as how and what to eat to control blood glucose, types of exercise for different ages and levels of fitness, how to properly check blood glucose levels, and how to prevent other diseases often associated with diabetes. Both anthropologists and health researchers from different disciplines have studied diabetes education programs in

order to assess their effectiveness in helping individuals adopt healthier lifestyles as well as manage aspects of their disease.

The American Association of Diabetes Educators (AADE) has stated that "the primary purposes (goals) of diabetes education are to provide knowledge and skill training, help individuals identify barriers, and facilitate problem solving and coping skills to achieve effective self-care behavior and behavior change" (Mulcahy et al. 2003:804). The AADE provides a list of seven behaviors for analyzing the efficacy of DSME in outcomes of patients (Mulcahy et al. 2003:809).

1. Being physically active
2. Eating
3. Medication taking
4. Monitoring of blood glucose
5. Problem solving, especially for blood glucose: high and low levels, and sick days
6. Reducing risks of diabetes complication
7. Living with diabetes (psychosocial adaptation)

Based on this set of behaviors, health-oriented studies generally conclude that DSME is effective in positive outcomes for patients upon completion of DSME programs. Hyun-Ko et al. (2012), for example, found that individuals with diagnosis periods of one year or less at the time of DSME have better outcomes overall after participation in diabetes education than do those individuals who were diagnosed three or more years prior to education. Behavior changes concerning diet and physical activity were shown to have improved significantly (226), however A1C levels reflected the most change in the <1 year group, with almost half (45.9%) of the group reaching target levels of <7%, compared to only 16.7% of the >3 years group (227). Other studies provide evidence that DSME does promote improved health outcomes for diabetes patients, particularly in glycemic control, lower cholesterol, improved diet, increased knowledge

of diabetes, self-management skills and self-efficacy and empowerment, and lower A1C levels (Steinsbekk et al. 2012:15, Tang et al. 2012:1, 4, Hyun-Ko, 2012, Lorig et al. 2001). While important to this field of knowledge, many of these studies are not useful for making comparisons of DSME programs due to lack of uniformity between each program. Requirements for enrollment, costs, and curriculum may vary from program to program

Anthropological studies of diabetes, on the other hand, do not usually evaluate the effectiveness of DSEM programs. Instead, they tend to focus on one of two broader topics: describing and analyzing the self-care behaviors used by individuals or on how particular ethnic or disparities subgroups manage diabetes. Hunt and Arar (2001) for example, conducted a study of the contrasting perspectives of diabetes management among patients and health care providers in south Texas. The researchers used detailed individual interviews to explore how individuals think about their disease, and how providers see their patients. Schoenberg et al, (2008) focused on comparing self-care behaviors among older adults from four ethnic groups. They found that each group, African American, Native American, Mexican American, and rural Whites had similar self-care behaviors. Another study by Smith (2011) explored how cultural beliefs about food, disease causation, and religious faith influenced diabetes self-care behaviors among Afro-Caribbean women in the United States. Finucane and McMullen (2008) also focused on a specific ethnic group with their study on Filipino Americans in Hawaii. They were concerned with understanding how culture influences self-care, and how to use that information to design culturally relevant DSME for this population. Guell (2012) looked at how Turkish migrants in Germany navigate healthcare with the disadvantages associated with their marginal status. These examples demonstrate that anthropology is valuable to gain detailed knowledge about how particular groups understand and cope with diabetes, and can be used to design more meaningful

and relevant educational programs. However, these anthropological analyses seldom look at existing programs to try and determine why some people use them and others do not.

The problem in most public health settings, and in particular for the Pitt County health department, is not evaluating the effectiveness of DSME, but with improving rates of patient utilization and retention to the programs. What barriers prevent individuals with diabetes from attending DSME programs? Time and costs associated with the program, lack of transportation, and a misconception of the usefulness of DSME are all factors that have been revealed in previous studies (Peyrot and Rubin, 2008:93, Graziani et al. 1999:361).

One of the primary factors that prevent individuals from attending DSME programs is a lack of understanding, about not only their efficacy, but also about how such programs work. This barrier is a multifaceted one. Minimal encouragement from physicians about the importance of diabetes education may prevent patients from committing themselves to a DSME program. Many times, the physicians themselves may not have a proper understanding of DSME, and therefore are not able to share this with patients. Age and level of education can also affect how a patient perceives DSME. Often, older patients are less willing to try new approaches to care, and only want diabetes information from their primary care doctor. Low levels of education may also affect how an individual perceives DSME, as they may not have the opportunity to resources that assist them in understanding its efficacy. In a 2009 study, Peyrot et al., conducted telephone focus groups and internet surveys to elicit perceived barriers to DSME from diabetes educators, physicians, and individuals with diabetes. This study revealed levels of misconceptions from each group. The diabetes educators most frequently believed that physicians did not recognize the importance of DSME, or thought that it did not work, and therefore did not encourage their patients to attend. Physicians however, perceived DSME as ineffective because they feared that

patients were being taught incorrect ideas about diabetes management. One example of this was a DE telling a patient that the target A1c level was <8%, and the physician wanted it at <6%. Furthermore, many of the doctors in the study found the referral process to be complicated and also thought that their patients were not interested in DSME. Patients said that their doctors did not think DSME was important and therefore they did not either (2009:256). (Graziani et al. (1999) found that patients were more likely to attend DSME programs if their doctor emphasized its importance (360). This cycle of misconception should be addressed in order for physicians and diabetes educators to be in agreement, and better serve individuals with diabetes. Peyrot et al. 2009 found that patients were more likely to believe that they did not need education because they could get the information from their doctor, or already knew what they needed to know to manage their diabetes. Some patients not on insulin treatment and who had no prior DSME expressed the idea that DSME was not for them, because only people on insulin needed that type of education (256).

An individual's prior knowledge about diabetes, including its cause, may greatly influence management practices. Notions of etiology are often rooted in cultural or folk traditions (Smith, 2011, Finucane and McMullen, 2008). These beliefs may deter patients from seeking treatment or DSME because they do not believe that it will help (Peyrot et al, 2009, Maine Department of Health and Human Services, 2006). Conversely, cultural beliefs may dictate that self-management of disease is important, and is a desirable and obtainable goal. Truong et al. 2011) found that beliefs about the cause of diabetes in a Vietnamese speaking community in Oklahoma City led them to desire DSME to manage their disease. (88,82). Level of education and socioeconomic status are often co-occurring factors, and both may influence knowledge and beliefs about diabetes (Cauch-Dudek et al. 2013, Hunt and Arar, 2001).

Individuals with any chronic disease are faced with increased costs of care, and those with diabetes are no different. Often, individuals with diabetes cannot afford the cost of basic disease management, much less the extra cost of DSME (Hunt and Arar, 2001). Many must take medication and insulin on a daily basis, and because of an elevated risk of for other health problems, many are also on medication for other conditions such as high blood pressure. Financial barriers are frequently mentioned in other studies. Every program has differing regulations on what types of insurance they accept, or if they include Medicaid and Medicare, which makes it difficult to properly compare all DSME barriers. Peyrot et al. 2009 found that many individuals did not have health coverage to assist in the cost of a DSME program. Balamurugan et al. (2006) found that if people have to pay for a DSME program; they are less likely to participate. A study conducted by the Maine Department of Health and Human Services examined the perceptions of non-attendance in their DSME program. Physicians, diabetes educators, and individuals with diabetes who had not attended a DSME program were surveyed. Interestingly, they found that only the physicians and diabetes educators, not the patients, perceived cost as a significant barrier (2006:32). Most studies of barriers produced by health researchers use surveys to determine whether individuals or providers agree that a predetermined list of factors may inhibit access to or use of services. Lacking from this literature is research that directly asks diabetic individuals to talk in-depth about both their perceptions of these programs and their reasons for attending or not attending. One methodology that could be employed to address these questions is the use of focus groups.

A focus group is defined by Robinson (1999) as “an in-depth, open-ended group discussion of 1-2 hours’ duration that explores a specific set of issues on a predefined and limited topic” (905). She also states that focus groups typically consist of between five and eight

participants. This research method originated in the field of marketing and involves group interviews designed to elicit discussion of various topics. Marketers used focus groups to gage consumer reactions to new products. Since that time, focus groups have been used in social science for exploratory research (Stewart and Shamdasani, 1990:15) and for gathering data on attitudes, beliefs and opinions about a particular topic (Dawson, Manderson and Tallo, 1993:9). Focus groups may reveal information about the factors that influence the decision to seek out and continue diabetes self-management education, as seen in the 2009 study by Peyrot et al. Furthermore, Dawson, et al. (1993) state that focus groups are useful for health education programs, as they provide a chance for the study population to explain *why* they feel as they do (9). Data collected from focus groups is frequently used in evaluating health education programs, as well as solving specific problems within a program (Dawson, Manderson, and Tallo, 1993:10). There are numerous advantages to utilizing a focus group. The researcher has the ability to gather information from multiple people in a short time, as compared to conducting individual interviews, and the data is straightforward and easy to analyze (Stewart and Shamdasani (1990:16), Robinson (1999) says that participants enjoy the more relaxed and natural setting of a focus group, and that it often gives them a sense of empowerment when they share their thoughts and feelings (909). This method is not without limitations however. According to Stewart and Shamdasani (1990:17), one limitation of this method is the small number of respondents, and the associated risk of an inaccurate representation of the larger population. There is also the risk of bias, both from having a group of strangers discussing possibly personal topics, and from the moderator unintentionally giving cues to the types of answers they are seeking. The moderator must be careful, in order to make sure all participants

have an opportunity to share, and not let one outspoken individual take control of the conversation (Robinson, 1999:909).

Findings of participant observation

Prior to the focus group, I gained insight into perceptions of barriers to DSME from both patients and health professionals during patient appointments, classes, support groups, and meetings, as well as engaging in discussions with DSME directors. From these experiences, I began to assemble ideas about patient barriers and found that they were similar to those found in the literature that I reviewed, for example, the unfeasible cost of the program and problems with access to transportation to education sites. In some instances, these issues were interconnected, creating multiple barriers for patients.

The main concerns for patients were cost, time commitment, and transportation to the program. The Pitt county health department serves a high poverty area and the fees for people not covered by Medicaid or insurance were higher than many could afford. During a webinar that I observed with my supervisor, I learned that although Medicaid does fully cover the cost of DSME, it only pays for ten hours in the patient's lifetime (Notes 8/7/13). To establish the cost, they must bring financial documents and provide information on the number of people in their household to the business office during the initial appointment. Several people were frustrated at not having been told how much it would cost before coming to the initial appointment. During one initial appointment, a patient discovered that it would cost sixty-four dollars for each class. She was very adamant that she could not afford this, and would not be coming to the classes (Notes, 6/12/13). The support group was mentioned by one patient to be helpful, but she wished they would cover topics from the classes since she could not afford the cost of the program

(Notes, 8/5/13). The cost of, or access to, transportation, such as having a car, gas and bus fees were also expressed as a concern several times, as I will discuss in the following section.

The time commitment to the program is a minimum of eleven hours, one hour for the initial intake, eight hours for the two classes, and two hours for the three month follow up class. Each of these is held between 8 am and 5 pm, during typical work and school hours, creating scheduling conflicts for many patients. In addition to this, the time that it takes to travel to and from the health department is frequently an additional barrier. Most patients live in Pitt County, although there are some that come from surrounding counties. The distance to travel can be up to 30 miles each direction. For those who do not have access to a vehicle, they must rely on public transportation, which is only available within Greenville. The bus runs once an hour, at :39 on the hour, however, the classes start at 12 pm, and end at 4 pm, forcing the patients to wait about an hour in addition to the time already spent there. I took the bus several times to and from the health department, and what was a maximum of a ten-minute drive took about two hours by bus, with only one transfer. Some areas of south Greenville require two transfers. The cost of the bus is two dollars per ride, or a day pass can be purchased for the same price. For some patients, this is unaffordable. One woman relied on a social worker to provide her with a bus pass in order to come to the program, but that was not a simple process, as we had to call the social worker to confirm that the patient had a medical appointment before it could be given out to the patient.

During the initial intake, the classes and support groups, patients were most interested in learning about food, and secondly with medications. This was a point of contention for patients, as they were expecting this information during the initial, but it is not fully presented until the second class. Many patients want to discuss their medications with the diabetes educators (DE), and ask advice about changing their treatments. According to the educators however, this is a

topic best discussed with the individual's primary care physician. This is a prime example of the lack of understanding about the purpose of the DSME program. The educators also take blood pressure and weight measurements during the initial, which adds to the patient's confusion of the roll of the educator. During both the classes and the support group, conversation tended to deviate away from the set topics onto food and medication, which the patients enjoyed, but the educators expressed to me that this is not a desirable situation, because they could be sharing inaccurate information among one another. I overheard several conversations during classes and support group that confirm these concerns, for example, one patient said that soaking potatoes in water overnight would take the starch out of them, so they wouldn't affect blood sugar levels (Notes 7/1/13).

From the perspective of the diabetes educators and other health professionals that I talked to, there was a consensus that program costs were a significant barrier to diabetes education. Frustration at the lack of resources available to assist patients was frequently expressed, and there were many discussions about how to remedy this situation. For example, DSME program directors were in the process of obtaining Medicare coverage for the program to increase the number of potential patients who would not have to pay out of pocket. They were also working with representatives from blood glucose monitor companies to obtain free products for patients. The DE's perceive a lack of communication between primary care physicians and patients about the importance of DSME, which may affect the willingness of the patient to commit to the program. A patient stated during one class that her doctor told her to come to the program, and then come back with any questions (Notes 6/17/13). That statement leads me to think that there is a disconnect between the physician and the DSME program, which is not advantageous to the patient.

Focus group

Process

At the request of the DSME directors, I designed a focus group to research the factors that prevent referred patients from attending and/or completing the DSME program. The first step in this research was to complete an Institutional Review Board (IRB) submission to ensure that the research subjects would not be in any physical or psychological harm during or after the course of their participation. This included an Informed Consent form that each participant would sign at the beginning of the focus group (Appendix A). I met with Kenneth Briley of the UMCIRB office for assistance on completing the IRB form. The IRB was submitted on July 1, 2013, and was approved on July 25, 2013 (Appendix B). During the period between submitting the IRB and obtaining approval, I sought out donations for a raffle that was held following the focus group. This involved first writing a donation request letter and having it approved by Dr. John Morrow, the health department director, in order to have it on the health department letterhead (Appendix C). I then chose local businesses that I determined would have products that an individual with diabetes could use in managing their diabetes. Three gift baskets with diabetic products such as socks, glucose tablets, and alcohol wipes were donated by two local pharmacies. Seven gifts cards were provided by four grocery stores in Greenville. Each person was able to receive a gift upon completing the focus group session. The remaining two donations were given to the DSME program to use in the future.

I developed a list of potential participants from the health department database. Criteria for eligibility included having been referred to the DSME program between January 1, 2012, and March 2013. Although the program began in 2009, my supervisor and I decided that trying to contact people from that far back would not be practical. Other criteria were that a minimum of

three months had passed since the patient's last visit, or more than five attempts at scheduling the patient for the next visit were unsuccessful, the patient's case was then considered "closed", and they were eligible for the focus group. Based on these criteria, I compiled a list of seventy-three potential participants. Twenty-five were patients who had attended at least the initial appointment but had not completed the three-month follow-up, and 48 were patients had been referred but had never been seen by one of the diabetes educators. After being approved by the IRB, I began making phone calls to the individuals on the list (Appendix D). Over the course of two days, I attempted contact with all seventy-three individuals. Of these, ten phone numbers were no longer in service, and four had changed phone numbers. I left fourteen voicemail messages with no response. Four patients did not have a message service. I initially had seventeen confirmed for the focus group, and informed each of them that I would make reminder calls the day before the scheduled time. Upon making reminder calls, two dropped out, and five confirmed with a "maybe" leaving fifteen potential participants. On the day of the focus group, nine people attended, including eight participants and one child of a participant.

The demographics of the participants were recorded in the survey provided at the conclusion of the session and through questions asked during the session. One participant did complete the demographic survey, therefore health care coverage is not known for this individual. There were three males, two African American and one Caucasian, and five females, all African American. Participant age ranged from 31 to 70. Two were between thirty-one and forty, three were between fifty-one and sixty, and two were between sixty-one and seventy years old. Duration of disease ranged from four months to thirty years and included both type 1 (n=2) and type 2 diabetes (n=6). One participant had both Medicaid and Medicare coverage, three had

only Medicaid, one had private insurance through place of employment, and one had no health coverage.

Through collaboration with Joan Mansfield, Robin High, and Holly Mathews, the final interview guide had eleven questions (Appendix E), although question four was skipped during the session due to time restraints. The questions were designed to first explore the participant's experiences with diabetes, including how their primary care physicians have helped them and how they feel about having this chronic disease. The second portion of questions was focused on their experiences with the DSME program and support group in order to gain insight into the barriers that prevented them from participation in the program, which was the main goal of this research. The final question was designed to discover new methods of advertising to the community in order to increase public knowledge about the DSME program.

Upon arrival, each participant was welcomed, and offered lunch and drinks. They were then given a raffle ticket for the drawing held once the session was completed. Once everyone was seated, I explained that I would be recording the session, and began taping. The recorded time was 1:10:32, including the raffle. We first went through the consent form and had everyone sign it. They handed the signed copy to me and kept a blank form. At this point, I formally introduced Dr. Holly Mathews and myself, and began the interview process. Participants introduced themselves, which transitioned into the first question on the duration of their disease. The session strayed off topic several times, but each time I was able to guide everyone back to the discussion question. As previously stated, I omitted question four, "Who else has helped you to manage your diabetes? Where do you get information about diabetes?" More time was spent on previous questions than I had anticipated, and to some extent, the question was answered during discussion of the previous questions. Several participants expressed that they enjoyed the

session, particularly the opportunity to discuss their experiences with people in similar situations. I sensed that several participants were confused about the goal of the focus group, and treated it more as a support group.

Results of Focus Group

Upon analysis of the focus group session, three themes emerged from the data. Lack of financial resources, time limitations, and misunderstanding of the program are the main barriers to care for this particular population. These barriers reflect those found in previous studies, as I have shown in the literature.

For the participants of the focus group, the cost of the program was a concern. Medicaid currently covers the cost of the program and some private insurance companies will pay the fees as well. The health department is working to expand coverage to include Medicare, but as of the end of my internship, this had not yet been approved. For those who are not covered by the previous options, the cost of the program is based on a sliding fee scale determined by income and number of people in the household. This is done at the financial office following the initial appointment with the DE. During the focus group, the participants voiced their confusion about the costs, and that they did not like not knowing how much they would have to pay before coming to the initial appointment. One individual stated that even fifteen dollars per class was too much to pay, particularly with the additional costs of managing his diabetes. Another participant lost his job as a truck driver after being diagnosed, and his insurance does not cover the majority of his costs associated with diabetes, including insulin and testing supplies.

The time required for each class was a problem for all of the participants. The first two classes are four hours each and are held from noon to four pm. The two follow up classes are each two hours long and are held at noon as well. Some expressed that they could not take this much time

out of their day, due to work schedules or needing to take care of children at home. One individual had to take a day off work to go to the initial appointment. More than half also said four hours is too long to sit and learn so much new information, and that it was overwhelming. One participant stated, “They act like you don’t have a life”. They would prefer several two-hour classes that cover one or two topics each. Several participants said that the time of day, noon to four pm, was not convenient; however, there was no consensus as to what time would work for all patients. Some people also indicated that the need to use public transportation to travel to the health department added additional time to their day. The health department is located in the north part of Greenville, and can be a two hour round trip by bus. Greenville is in the middle of the county, and the travel time to the health department can be up to thirty miles one direction. I had expected lack of transportation to be a common barrier, but I must take into consideration that the people who were able to come to the focus group most likely do not have problems with transportation. One woman who I spoke with during the recruitment process was not able to come to the focus group because she does not drive, and stated that she does not have access to transportation because she does not live in Greenville.

In focus group discussions, participants seemed to lack an understanding of the overall purpose of the program and why it would be helpful to someone with diabetes. During the session, those attending wanted to discuss medications and which ones worked best with the fewest side effects. It seemed clear, that even when physicians had recommended the program to them, its purpose had not been explained in detail. When. I asked what their primary care physicians told them about the program at the time of referral; the majority said, simply, “nothing”. Another stated that her doctor told her, “it is a nice program, and I might benefit from it”. Participants also indicated that their physicians never really gave them much information

about diabetes or the importance of self-management. For example, several said they were told at diagnosis to “watch what you eat”, “lose weight”, and “exercise”, but not how to actually perform these tasks. One participant specifically asked her doctor for more information and was told to look on the internet, which she said left her more confused than before, due to the conflicting types of information she found .When one participant was diagnosed with type 2 diabetes a year and a half ago, her doctor told she had been pre-diabetic for about five years. She said that she had not been told this before, and was very angry because she would have come to the program then if she had known about it in order to prevent the disease from getting worse.

In addition to suggestions about the length of classes, participants also observed that what they really liked about the focus group was the opportunity to talk with other people struggling with a diagnosis of diabetes. They said it had really been helpful to hear what changes others were making in diet, what types of medications they were taking and how these worked, how they liked their physicians and nurses and even how they were coping in their daily lives with the disease. These participants said more interaction in the classes with other patients would be helpful and seemed to want a support group for help. Clearly, most did not know that the DSME program already provides a support group open to those who are and are not enrolled in the classes. Two people had been to the support group and mentioned that they enjoyed it and benefited from it.

Recommendations for the Program

Based on the information gathered from the focus group and my own observations of the program and the classes, I think there are some steps that might work to increase patient participation and retention in the program. To address problems with transportation costs, working with the Greenville Area Transit (GREAT) to obtain bus passes for those in need could

eliminate the problem of affording a bus pass. I also suggest establishing a system to determine the cost of the program for each patient before the initial appointment to eliminate the confusion about this barrier. If this could be done over the phone prior to coming into the office, it could make the initial encounter less stressful for the patient. More emphasis on explaining the content and objectives of the program and the classes during the initial intake appointment might help foster understanding and buy-in by the patient. If the patient knows what to expect, and understands how the program will aid in managing their diabetes, they might be more enthusiastic and willing to attend. Similarly, clients need to be made aware of how the support group differs from the classes. Somehow, they are not understanding even when they have been told about it. One possibility might be to make attendance at one support group meeting mandatory for participation in the program. Once clients have attended a session, they may realize that the support group is helpful and it could ensure better future attendance for those sessions.

In order to address the barrier associated with physicians not emphasizing the importance of the program, a collaborative effort must be undertaken. A brief presentation of the importance of the program could be given to local physicians, including statistics on DSME success in lowering A1c levels, reducing the risk of associated diseases, and improving overall health. It was also discussed in the focus group that nurse practitioners often spent more time with the patients than did the doctors, so a two-pronged initiative might be more effective. A presentation could be designed to encourage physicians to recommend referral to the program, but nurse practitioners and PAs in large practices could be educated about the purpose of the program and asked to reinforce the physician recommendation with patients. Two participants in the focus group mentioned receiving more, and better, information about diabetes from their optometrists

than from their primary care physician, which could be an additional avenue to explore for promoting the DSME program. In today's world of fragmented care, people with diabetes often see a number of specialists. In addition to optometrists, many also see podiatrists for foot care or receive assistance from the wound center. All of these might be other avenues for publicizing the program. The curriculum itself could be modified to include more discussion of medications so that patients' feel more empowered and knowledge in interactions with their health care providers.

The last question I asked during the focus group was for their suggestions on how to better advertise the DSME program to the public. Several methods were discussed, including putting the information out in doctor's offices; radio, television, and print advertisements; and announcements in churches and other public places. Information sessions in major churches could reach many people who are pre-diabetic and who might then be encouraged to ask their physicians about the program. Respondents also mentioned other public places for disseminating information including barbershops and hair salons, grocery stores, and public libraries. An additional source for partnership is the Third Street Community Center in Greenville. While this organization focuses on youth, the administrators have held successful international fairs to advertise services for the Latino community and a similar event focusing on health issues generally or diabetes in particular could potentially reach a major segment of those known to have diabetes in Greenville since a larger proportion live in this neighborhood.

Skills Acquired in the Internship

This internship has provided me the opportunity to improve certain skills, as well to acquire new ones, which will assist me in beginning my career as an anthropologist. My goal has been to work in a health advocacy position, and the experiences that I had during this endeavor

have taught me both the struggles and successes of working in a health care setting. I have seen that you cannot always provide the assistance needed due to financial and legal restrictions, and I have a better understanding of how to work with people in a variety of roles within the health care system. These are valuable lessons that I am fortunate to have experienced before entering the workforce. I have expanded my knowledge of the public health system and the services it provides to the community. I learned how to approach health disparities and chronic disease management from a collaborative perspective by involving numerous community groups and health offices to solve problems. In addition to the experiences that have added to my knowledge of health care systems, I have also enhanced my skills as a professional anthropologist. For the focus group, I completed the East Carolina University Institutional Review Board application and human subjects' modules. This included developing a consent form necessary for research with human subjects. I collaborated with my supervisor to design a focus group interview instrument, and learned how to recruit participants for the focus group. I worked to solicit appropriately from businesses for support in a project. I also learned how to administer an interview guide and moderate a focus group. I worked to refine my skills in participant observation, interviewing individuals one on one, and in analyzing data. I learned about the structure of a public health department, the positions of authority within it, and how to navigate these in order to gain approval for a project. I was trained to operate an unfamiliar database management system, and to navigate the file process. I improved my communication and presentation skills by developing a report as well as a poster presentation on the findings of my research to present not only to your academic department but to health department staff as well. I will also present this research in the ECU Research and Creative Achievement Week and the Society for Applied Anthropology conference.

Conclusion

Through the course of my internship experience, I have had the chance to reflect on the role an anthropologist could play in a public health setting and with public health initiatives. Most of the staff and program directors at the Pitt County Health Department are trained in health professions like medicine, nursing, and health education. Because of this, they tend to bring certain types of assumptions into dealing with clients who are usually from very different socioeconomic and ethnic backgrounds. In her book, *Cancer in the Community,* Martha Balshem (1993) reflects on her role as an anthropologist working in a health education outreach program in Philadelphia. She found that the physicians and health educators with whom she worked tended to accept portrayals of the working classes and of the poor that were ingrained into professional training. On the other hand, Balshem found that many health professionals, especially health educators, were often motivated by a genuine desire to help others and be advocates for the poor and underserved. Yet they were blind to the assumptions they often made that prevented or conflicted with this desire (1993:127). As an outside observer, the anthropologist, trained to utilize a holistic perspective, can often perceive some of these conflicts between professional orientations and the worlds of the clients. For example, it is often assumed by educators that people will put their health needs first and make them a priority in their lives. Yet many of the clients who attended the focus group talked about the realities of life with low paying jobs, financial struggles, lack of transportation, and children and others who needed their attention. For them, attending to personal health needs was often a much lower priority than other problems they faced daily.

Similarly, the orientation Balshem (1993:4) reported of health professionals to direct their efforts toward the “other,” the client instead of toward themselves was apparent in the DSME

program. While the staff acknowledged that they were not getting as many referrals as they would prefer from local physicians, they seemed unaware of the fact that many physicians made no attempt to inform their patients about diabetes, to help them understand the condition or the reasons why an educational program might be helpful. In this case, as an anthropologist looking in from the outside, I could see the need to concentrate efforts to medical professionals as much as to their patients in order to ensure that clients were motivated to join the program and complete the program. Another issue that I was able to perceive because of the holistic perspective engrained into anthropology was the impact that fragmentation of care has on follow through with patients and their needs outside of the medical setting. Even when physicians recommended the program, there was no one to follow through and make sure they attended. Many of the clients in the focus group talked about how little they discussed with physicians and indicated that nurse practitioners were more helpful because they were the office personnel they saw more regularly. It is also an issue for some that they may never see the same practitioner twice; therefore, long-term monitoring of how people are adjusting to diabetes is not usually going to happen. The DSME could play a vital role in this process, but it will need to target much more effort toward outreach to health professionals than it does at present.

Anthropologists are trained to embrace the framework of cultural relativity and cultural sensitivity. When providers work with clients from other nations who speak different languages, they are often more attuned to and tolerant of the existence of cultural differences. However, when providers work with people from their own communities who are separated by class and ethnicity, they are much less so. As Balshem points out, they are often likely to blame the very victims of poverty and discrimination for causing their own problems and at times look upon the poor and minorities as adversaries (1993:5). It would seem in these settings, medical

anthropologists have a crucial role to play in helping professional recognize their own biases by pointing out the difficulties that clients face and by describing the real hardships of their day-to-day lives. When you humanize a group of people, you can often provide the basis for a breakthrough in empathy and understanding. Anthropologists are in a unique position to help this happen. Alternatively, clients who may be living in different circumstances from professionals are often prejudiced against them as well. They may regard health professionals as arrogant, controlling, only concerned with making money, and may not understand why providers do what they do or why programs are structured in certain way. As cultural brokers, anthropologists also have the obligation to translate or explain professional assumptions to client populations in order to help facilitate mutual understanding and to help development shared treatment goals.

I have learned a great deal in my internship about the public health setting and about the role an anthropologist might play, but I know that I still have more to learn in the future. My goal is to obtain an applied job in a health advocacy setting and to continue trying to develop my skills to work with both health providers and patients to promote positive health outcomes.

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Appendices

Appendix A: Informed Consent

Title of Research Study: Perceptions of Attending a Diabetes Self-Management Education Program: A Pilot Study
Principal Investigator: Kenley Turney
Institution/Department or Division: East Carolina University, Department of Anthropology
Address: 231 Flanagan Building, East Carolina University
East Fifth Street, Greenville, NC 27858
Telephone #: 252.328.9430

Researchers at East Carolina University (ECU) study problems in society, health problems, environmental problems, behavior problems and the human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need the help of volunteers who are willing to take part in research.

Why is this research being done?

The purpose of this research is to understand and improve the diabetes self-management education program. The decision to take part in this research is yours to make. By doing this research, we hope to learn the reasons why people decide not attend the diabetes self-management education program at the Pitt County Health Department.

Why am I being invited to take part in this research?

You are being invited to take part in this research because you have been referred to the diabetes self-management education program by your primary care physician, but have decided not to participate, or you have begun the program but have not completed it. If you volunteer to take part in this research, you will be one of about 20 people to do so.

Are there reasons I should not take part in this research?

You should not participate in this research if you have completed the diabetes self-management education program at the Pitt County health department.

What other choices do I have if I do not take part in this research?
You can choose not to participate.

Where is the research going to take place and how long will it last?

The research procedures will be conducted at the Pitt County Health Department, 201 Government Circle, Greenville, NC. You will need to come to the Pitt County Health Department, 201 Government Circle, Greenville, NC 1 time during the study. The total amount of time you will be asked to volunteer for this study is 2 hours.

What will I be asked to do?
You are being asked to do the following: Participate in a discussion about the reasons that kept you from attending the diabetes self-management education program at the Pitt County health department.
The focus group will be audio recorded, but no names will be used. My advisor and I will be the only people that will have access to the recordings. The staff at the health department will not have access, and they will not know who participated in this focus group.

After signing this consent form, you will be given a short form that asks your age, sex, race/ethnicity, type of diabetes and information about insurance. This will help me to understand the population that the diabetes self-management education program serves.

I will then start the focus group. The types of questions that will be asked concern your thoughts about the importance of diabetes self-management, where you prefer to get information about how to manage your diabetes, and what are the major factors that kept you from coming to the diabetes self-management education program.

What possible harms or discomforts might I experience if I take part in the research?
It has been determined that the risks associated with this research are no more than what you would experience in everyday life.

What are the possible benefits I may experience from taking part in this research?

We do not know if you will get any benefits by taking part in this study. This research might help us learn more about the reasons that people choose not to participate in a diabetes self-management education program. There may be no personal benefit from your participation but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?
Yes, you will be given a $20 Visa Gift card when the focus group session is completed. There will also be a raffle drawing for door prizes help when the focus group session in completed.

What will it cost me to take part in this research?

It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?

To do this research, ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- The University & Medical Center Institutional Review Board (UMCIRB) and its staff, who have responsibility for overseeing your welfare during this research, and other ECU staff who oversee this research.

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections

How will you keep the information you collect about me secure? How long will you keep it?
The information that I collect here today will be kept secure. I will keep the paper files in a locked file cabinet. The audio recording will be kept in a locked file cabinet until I transcribe it, then I will erase and destroy the recording. All electronic files will be stored on a locked computer that only I can access. This information will not be used for any future study.

What if I decide I do not want to continue in this research?

If you decide you no longer want to be in this research after it has already started, you may stop at any time. You will not be penalized or criticized for stopping. You will not lose any benefits that you should normally receive.

Who should I contact if I have questions?

The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 252-902-2417(Monday through Thursday between 9:00 am and 2:30 pm.

If you have questions about your rights as someone taking part in research, you may call the Office for Human Research Integrity (OHRI) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the OHRI, at 252-744-1971

I have decided I want to take part in this research. What should I do now?
The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

_____ _____ _____

Participant's Name (PRINT) **Signature** **Date**

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT)	**Signature**	**Date**

Appendix B: IRB Approval Letter

To: Kenley Turney

CC: Holly Mathews

Date: 7/25/2013

Re: UMCIRB 13-001357
Perceptions of Attending a Diabetes Self-Management Education Program: A Pilot Study

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 7/24/2013 to 7/23/2014. The research study is eligible for review under expedited categories #6 and #7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
Focus Group questions.doc	Interview/Focus Group Scripts/Questions
Informed-Consent-Template-No-More-Than-Minimal-Risk-03-28-2013.doc	Consent Forms
Recruitment script.doc	Recruitment Documents/Scripts
Turney Internship final.docx	Study Protocol or Grant Application

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

Appendix C: Donation Request Letter

PittCounty Public Health

Dr. John Morrow, Director

June 17, 2013

Dear IRB Committee:
I am very pleased to write in support of Kenley Turney's Masters project, "Perceptions of Attending a Diabetes Self-Management Education Program: A Pilot Study", for the Department of Anthropology at East Carolina University. Kenley Turney has discussed this project with representatives of the Pitt County Health Department.

The Diabetes Self-Management Education (DSME) Program offered at the Pitt County Health Department, an American Diabetes Association-certified program, includes 10 hours of diabetes education offered on a sliding fee scale to both insured and uninsured persons with diabetes. The DSME program is an opportunity to work with the patient and his or her physician to provide comprehensive diabetes management. Ms. Turney's project is an opportunity to explore factors that inhibit participation in the Diabetes Self-Management Education program and hopefully will reveal opportunities in which we can increase both patient participation and retention.

Following approved review by the Institutional Review Board, Ms. Turney will be granted full access to medical records, in order to conduct focus groups and phone interviews involving our patients in the Diabetes Self-Management Education Program as part of her Masters project.
Sincerely,

John Morrow, MD, MPH
Director, Pitt County Health Department

www.pittcountync.gov
201 Government Circle Pitt County Office Park Greenville, N.C. 27834 252.902.2305 fax: 252.413.1446

Appendix D: Recruitment Script

Hello, could I speak to_____ please? *2

Hi, how are you doing today?

My name is Kenley Turney and I am a graduate student at East Carolina University. I am working with the Diabetes Program at the Pitt County health department. I am calling today to invite you to participate in a focus group. This is a chance for you to tell us what you think about the diabetes program at the Health Department.

[Patient may state that they never participated in the program and so will not be able to help. At this point, continue with the script below to explain why I have contacted him/her]

You have been chosen for this focus group because you(*1) have been referred to the diabetes program by your doctor, but have not started the program.

Your feedback would help the health department make improvements to the program, which may benefit you and your community.

The focus group will be held at the Pitt County health department on August 13th at 12 pm and lunch and drinks will be provided. Does this sound like something you could help us with?

A $20 Visa gift card will be given to participants when the focus group session is completed, and there will be a raffle for door prizes at the end as well.

If the patient states no, explain that all information will be kept confidential and your participation will not affect any current or future services that you receive at the health department.

Also, ask if they have any questions about the focus group or if a different time or day would work better.

If the patient still states no, politely thank him/her for their time and say goodbye.

If patient states yes→"thank you for your willingness to participate. All information will be kept confidential and your participation will not affect any current or future services that you receive at the health department.

Reiterate, "The focus group will be held at the Pitt County health department on August 13th at 12 pm.
I will call you the day before as a reminder.

Do you have any questions for me at this time?
Thank you for your time / participation, have a good day.
*1- you have started the program but have not yet completed it.
*2 – If patient is not at home or you get voicemail – Will leave a brief message to return my call at 252-902-2417 (office phone).

Appendix E: Focus Group Guide

Welcome and introductions
Sign consent form

1. How long ago were you diagnosed with diabetes?
2. What kinds of adjustments and changes have you had to make in your lifestyle since being diagnosed? <probes: eating habits, activity level, family dynamics>
3. Did your doctor give you any advice or guidance about what you should do to control/manage your diabetes?
4. Who else has helped you to manage your diabetes? Where do you get information about diabetes?
5. How do you know when you have your diabetes under control, and how do you know when it is not under control?

Change focus to the diabetes education program at the PCHD.-

6. Think back to when your doctor first suggested that you come to this program- Did your doctor tell you anything about the program? What do you remember him/her saying about it? What did you expect the program to be like?

7. For those of you who have never been to any part of the program, including the initial assessment, can you tell us about why you did not come and factors that might have encouraged you to come?
8. For those of you who did come to only the initial assessment but never came to the classes, can you tell us about your experience? What did you think about the program at that point? When did you decide not to attend the classes? Why?
9. For those of you who attended at least one of the four-hour classes, what were your opinions about the class? What did you like/dislike?
10. Do you know about the free monthly support group held here at the health department? If so, have you ever been?
11. We would like your opinions and suggestions about how we could better advertise the diabetes education program <probes: newspapers, radio, doctors offices, etc>

Conclude focus group, hand out demographic survey, give gift cards and complete the raffle.